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ABSTRACT

This report is one facet of an on-going effort to delineate, describe and analyze the current status of foster home care for adults in the U.S. Foster home care attempts to maintain the resident's normal life functioning within a family setting. It involves the use of a private family residence for the care of non-related aged or infirm persons. Supervision or assistance with feeding, toileting, or personal hygiene is given, but professional nursing services are not usually provided. The report reflects a survey conducted by the authors to answer several questions about the extent and nature of Adult Foster Care facilities and planning agencies, including whether they are licensed and how much interest seems to exist. Details of their findings are presented, as well as a list of tentative conclusions. The need for more information regarding all facets of AFC is emphasized. (Author)

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# INVISIBLE INSTITUTION: ADULT FOSTER CARE IN THE U.S.A.*

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## Introduction

This paper describes the attention given adult foster care (AFC) services in the planning activities of state offices or aging and local health planning agencies. The purpose is to define the environment in which AFC programs are planned and implemented as an alternative to institutional care of the minimally impaired elderly.

This report is one facet of an on-going effort to delineate, describe and analyze the current status of foster home care for adults in the United States. The authors define AFC as

> ". . . the use of a private family residence for the care of non-related aged or infirm persons requiring supervision of or assistance with such essential tasks of daily life as feeding, toileting or personal hygiene. No professional nursing services are provided routinely though such might be arranged to meet the temporary need . . . The focus of adult foster care is on the maintenance of the resident's normal life functioning within a family setting."[1]

Clearly foster care is of special interest as one option available to the older person who hopes to remain a part of the community while availing himself of needed supportive services.

The authors' previously reported research indicated the need for study of the planning processes which undergird AFC services and included the following findings:

- AFC is in fact a national phenomenon;
- numerous state agencies are often involved in the planning, administration, utilization and supervision of any single AFC program, a complicated and confusing picture of questionable impact on both care providers' and residents' lives;
- there has been little training of AFC operators;
- the magnitude of interest in AFC as measured by requests for information and training materials is great;
- there are major differences between the emphases placed by states with

licensure regulations as opposed to those with no such formal procedures which may impact directly on the quality of care provided.[2]

These findings, combined with the paucity of literature regarding AFC, raise questions about how and by whom AFC services are being planned. Have foster care programs "grown like topsy" or have they been integrated into the institutionalized planning mechanisms of states and regional groups?

From this general conern, the authors derived several specific research questions:

1. To what extent are health planning agencies and state offices on aging aware of functioning AFC services as an alternative for the minimally impaired elderly?

2. What functions do health and aging planners reportedly perform regarding adult foster care services?

3. Does the pattern of organizational control (licensure based on statute as opposed to sponsoring agency program guidelines) effect the amount of involvement in AFC programs by health and aging planners?

4. Do planners identify additional and/or different functional foster care programs from those previously reported by state departments of welfare, health and mental health and retardation?

5. Do health and aging planners demonstrate a significant interest in research or training regarding AFC?

The answers to these questions should suggest strategies for influencing public policy regarding AFC. These answers should then have special meaning for those who are interested in the benefits of foster home placements and concerned with upgrading the quality of care offered in these settings.

## Review of the Literature

No systematic approach to the study of foster home care for adults has previously been undertaken. The historical development of adult foster care has been described by Sherman and Newman.[3] Some studies mention foster homes as one alternative to institutionalization, without elaborating on this form of care.

Bradshaw, et al have described the characteristics of foster home operators and their residents in one locale.[4] Some attention has been paid to special programs for operators and their residents.[5,6]

One interesting addition to the literature is the Senate report of the Subcommittees on Long-term Care and the Health of the Elderly and the Special Committee on Aging, entitled Mental Health and the Elderly.[7] While the testimony focuses on older persons who are clients of the mental health sytem, it also represents opinion regarding foster care services for other minimally impaired adults. Most witnesses present entirely negative descriptions of foster care:

> "From the perspective of civil liberties, as well as health care, of the two sides of the right-of-treatment concept, such facilities as foster care homes have even less protection than do mental hospitals. They are repressive; there are no commitment procedures. Social Security checks may disappear into the hands of operators."[8]

Foster care is generally presented as a "dumping" option, an easy alternative to more expensive institutional care and offering little to the older person's quality of life.

Patricia Wald, litigation director of the Mental Health Law Project, lists problems encountered in small residential facilities in Washington, D.C.[9] This list is remarkably similar to the factors discussed in the authors' preliminary report of findings regarding the national status of adult foster care.[10]

On the other hand, the Senate report provides almost no mention of the strengths to be found in adult foster care. It is interesting to note that no foster care providers testified before this joint senate hearing: This is perhaps a further indication of stigmatization. Whether the depiction of AFC in almost entirely negative terms is accurate is a question for social scientific

analysis. Our working hypothesis is open: Factual investigation will contribute to the knowledge base, both positive and negative, regarding foster care operators and their elderly residents.

## Methodology

In April, 1976 a cover letter and brief eleven-item questionnaire were sent to all 222 local (314-B) health planning agencies operational in 1975. The authors were aware that the transition from 314-B to Health Systems Agency (HSA) status would complicate this survey method, but hoped that mail forwarding procedures would minimize this problem. A follow-up letter to non-respondents, including the questionnaire, was sent in August, 1976 with a special request for the name and address of the appropriate HSA if the 314-B agency were no longer operational.

In August, 1976 a cover letter and slightly revised twelve-item questionnaire were sent to the state offices on aging representing the fifty states and the District of Columbia. The revisions were made to reflect statutory differences of activities of health and aging planning agencies. Because of difficulty identifying comparable offices on aging, the authors submitted the survey to those specific state agencies designated to implement the Older Americans Act Program.

The survey instruments were designed to elicit specific information: awareness of operational AFC programs, specific agency activities performed, participation of adult foster care operators or residents on boards or committees, awareness of operator training and client matching systems, and planners' interest in receiving additional information regarding AFC.

For comparative purposes data analyzed were divided into the three catego-

ries established in previous research: states with licensed adult foster care programs, states with unlicensed adult foster care programs and states reporting no form of care comparable to the authors' operational definition of adult foster care.

Two states (Alabama and South Dakota) which did not respond to last year's study are now included in the unlicensed (AFC) category based on replies to the current surveys. Four states (Connecticut, Idaho, Tennessee and Oklahoma) previously identified as offering no form of care comparable to AFC are now included in the unlicensed foster care classification. Data from responding offices on aging and health planning agencies clearly support this change in categorization.

A number of other states report transitional status: changes planned but not yet in effect. Both Tennessee and Vermont are in the process of implementing licensure. Colorado's Adult Foster Care program is in transitional funding status. Massachusetts is closing its AFC program for the mentally ill, but developing one for the elderly. Finally, information from Washington state clarifies that licensure is required only for those adult foster homes which serve the retarded; foster homes available to the general elderly population are not subject to licensure. The survey instrument did not request this information on specific program changes. The program change descriptions provided by respondents are indicators of the need for some permanent mechanism to monitor shifting program characteristics in AFC.

All data were analyzed to compare responses for licensed vs. unlicensed states, health vs. aging planning groups. Percentages reported for awareness of foster care programs and requests for research and training materials were based on the total number of respondents for any given category. Percentages for items

related to agency functions in relation to foster care, participation of providers or recipients of foster care on agency committees, and recognition of services supportive to foster care programs were calculated using a base of the number of respondents aware of AFC programs for the specific category.

## FINDINGS

The rate of response to both surveys was excellent. Table 1 summarizes the response rate for the health planning agencies (n=222) and Offices on Aging (n=51 / the 50 states and the District of Columbia/). Also included is a summary of the states represented by the health planning agencies' responses. All data are categorized by the form of AFC provided in a given state.

Table 1

RESPONSE RATE Type of Agency, Foster Care Licensure Requirements and Foster Care Programs

| | Offices on Aging | | Health Planning Agencies | | States Represented By Health Planning Agencies | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | %. |
| License Required | 18/23 | 78 | 59/99 | 60 | 21/23 | 91 |
| No License Required | 16/24 | 67 | 67/110 | 61 | 20/24 | 83 |
| No Form of Adult Foster Care | 4/4 | 100 | 7/13 | 54 | 3/4 | 75 |
| Total Response | 38/51 | 75 | 133/222 | 60 | 44/51 | 86 |

The high rate of response from State Offices on Aging was especially gratifying

n view of the lack of a follow-up effort. Also meaningful was the distribution of states covered by the responding 314-B/HSA's since these replies represent a spectrum of control structures for AFC homes.

A large number of respondents not only completed the survey instrument but also submitted materials to represent their agencies' activities in relation to AFC programs. Twelve offices on aging (41% of those aware of AFC programs in their states) enclosed materials, primarily descriptive and policy statements. Fifteen of the health planning agencies (20%) also enclosed supporting materials, largely planning documents studying the distribution of foster care facilities in various regions, the use of foster homes as an alternative to institutional care, etc.

The excellent response rate combined with the variety of supporting materials submitted confirm the high level of interest in AFC noted in previous research.[11] This interest level is further confirmed by the number of respondents requesting the authors' research findings: 100 of all responding health planning agencies (75%) and 34 of the offices on aging (90%) asked for these reports. These figures may in fact be deceptively low as only 3% of the Offices on Aging and 9% of the 314-B/HSA's said they did not want the findings, leaving a sizeable gap of respondents who did not complete this item.

From these responses, some important directions and differences emerged. Although these findings do not lend themselves to the rules of statistical analysis of significance very strong differences in attributes concerning the functions of state Offices on Aging and 314-B/HSA's were found. Perhaps even more important for future study, many unanswered questions became apparent.

From an analytic and theoretical point of view, both state Offices on Ag-

ing and Health Systems Agencies should be involved in the development, planning and monitoring of foster home care for adults. Minimally, they should be aware of this form of care if it exists in their states. If such care does exist, these agencies should also be involved to some extent in accountability, certifying, and reportorial tasks. Finally, such agencies should serve a function in working to upgrade the quality of care and developing uniform guidelines for this form of non-institutional care for the impaired adult, especially the elderly.

These data are particularly cogent in revealing the following facts:

1. There are strong differences between foster care programs which are licensed and those which are unlicensed. Offices on Aging report far more involvement in the functioning of unlicensed AFC programs than in those licensed. Health planning agency involvement does not vary greatly by this categorization.

2. 314-B/HSA's are involved to a large extent only on planning levels. They do not function on the levels of certifying, inspecting or monitoring. On the other hand, Offices on Aging, while also participating in the planning process, provide guidance in sustaining program guidelines and serve multi-purpose functions in relation to AFC.

3. States with licensed AFC are less likely to involve either HSA's or Offices on Aging in the on-going surveillance of care than those with unlicensed programs. The probable explanation here is that Offices on Aging are more involved in the direct administration of AFC in unlicensed programs than in those regulated by legislation.

4. There are reported distinct areas of overlap between the two types of agencies, while, at the same time, no analytic differentiation of function. What is particularly of note is that in general neither appears aware of func-

tional differences and responsibilities nor articulates awareness of integrative, coordinated planning and monitoring functions.

5. There are several highly important functions which neither assumes. Because there are no uniform guidelines as to division of function among agencies, it can only be assumed that these are either inexplicit or present a gap in services which are essential to insure quality of care for the residents of AFC. These functions include inspection, recommendation for approval or licensure, establishing an optimal bed ratio for AFC. Despite disparities among states, the overall finding points to(the disparities among states, the overall finding points to)the disjunction, service gaps, lack of coordination (or even interaction) among these two major agencies charged with the responsibility of program planning and development.

6. Consumers and care providers are only minimally involved in decision making processes in both agencies. Only 13% of the Offices on Aging and 24% of the health planning agencies in states requiring licensure reported consumer involvement. States not requiring licensure reported a higher degree of consumer participation: 31% for the Offices on Aging and 34% for the 314-B/HSA's.

## CONCLUSIONS AND QUESTIONS FOR FURTHER STUDY

We introduced this paper as one part of an on-going effort to delineate, describe and analyze the current status of foster home care for adults in the United States, specifically the planning and development mechanisms which undergird functioning AFC services. We submit the following tentative conclusions and questions for future study:

1. The significantly greater involvement of Offices on Aging in unlicensed foster care programs probably results from a shared organizational locus. Both

Offices on Aging and unlicensed foster care programs are usually located within umbrella-type Departments for Human Resources. We are trying to identify the shift in planning responsibilities when licensure based in statute takes effect.

2. The vast majority of health planning respondents were 314-B agencies rather than newly operational Health Systems Agencies. These 314-B agencies largely reported only a planning function, specifically the inclusion of AFC in the development of an areawide health plan. It will be important to monitor the changing involvement of HSA's as they become better established, especially in light of the increased responsibilities enumerated in PL 93-641 which establishes the HSA's.

3. Duplicatory efforts and major service gap areas between Offices on Aging and Health Planning Agencies are documented by this study. However, a small number of respondents did give indications of collaborative planning, for example, an Office on Aging staff member serving on a health planning residential care advisory committee. We will try to identify other patterns of cooperation and collaboration.

4. Minimal participation of AFC consumers and providers is also documented. Again it will be helpful to document changes in this area as the Health Systems Agencies develop their sub-area structures which must be composed of a consumer majority. The critical question is whether those involved in AFC can become part of that consumer majority.

5. This study documents the authors' previous findings that those involved with AFC demonstrate need and desire for information regarding all facets of foster care: administration, qualitative factors of services provision, evaluation and planning, supervision and training. A major effort is needed in the development of an information-sharing system among states.

6. The major unanswered questions regarding AFC are very basic ones: how many adult foster homes are there? How many residents do they serve? How are these homes distributed? These simple questions have proved most difficult to answer. With this study's identification of those organizations which accept specific planning and program development responsibilities, it should be possible within the next year to develop a sound quantitative estimate of the extent of AFC services currently provided.

In conclusion, this study documents the relative invisibility of adult foster care in the planning organizations for health and the aging. While most planners were aware of the existence of AFC, they reported little actual involvement in the functioning of foster home services. This lack of involvement renders the operation of AFC as invisible to planners at present - an identifiable alternative about which little is truly known.

## FOOTNOTES

1. Bradshaw, Barbara R., Helen G. Deines & Lucy S. Tyler. "A Study of Adult Foster Care in the United States: A Report of Preliminary Findings." Paper presented to the Annual Meetings, The Gerontological Society, Louisville, Kentucky, October, 1975, p.2.

2. Bradshaw et al., Ibid., pp. 11-12.

3. Sherman, Susan and Evelyn S. Newman. "Foster Family Care in New York State." Paper presented to the Annual Meetings, The Gerontological Society, Louisville, Kentucky, October, 1975.

4. Bradshaw, Barbara R., William VonderHaar, Virginia Keeney, Lucy Tyler and Susan Harris. "Community-Based Residential Care for the Minimally Impaired Elderly: A Survey Analysis," Journal of the American Geriatrics Society, vol. 24, no. 8, 423-429.

5. Smetson, Walter S. "Foster Mothers & Mental Patients," Mental Hygiene, vol. 48, no. 2 (April, 1970), p. 25.

6. Wohlford, Martha. "Adult Foster Care - A Unique Answer," Public Welfare, vol. 26 (July, 1968), pp. 224-226.

7. Joint Hearing before the Subcommittee on Long-Term Care and the Subcommittee on Health of the Elderly of the Special Committee on Aging, Mental Health and Elderly, 94th Congress, 1st Session (U.S. Government Printing Office, 1976).

8. Statement of Dr. Robert N. Butler in Mental Health and the Elderly, op. cit., p. 53.

9. Statement of Patricia M. Wald in Mental Health and the Elderly, op. cit., p. 39.

10. Bradshaw, Deines & Tyler, op. cit.

11. Ibid., p. 3.